

The Act allows information to be withheld if the Medical Practitioner has the view that the content could be harmful to the patient.

We are very proud to be able to say that the case study of our retired Chair Person, Diane Carlton was used in Parliament to illustrate the need for this act. It was written in Diane's notes that she had Munchausen's Disease even following her diagnosis and much needed multiple surgery. It proves that we can make a difference if we speak out about this painful and debilitating disease.

- Copies of GP records can be requested from your General Practitioners surgery.
- Copies of consultant records can be requested from the hospital where you were treated.
- Diagrams and drawings made of findings during surgery can be useful.
- Every hospital has someone to deal with these requests.
- There will normally be a charge for photocopying these records. This can be up to £50 depending on the number of copies made.

Since 1 April 2004 patients are entitled to a copy of any GP referral letter and letters written by consultants. You should be asked if you want a copy but if not feel free to request one. There is no charge for this.

It is a good idea to keep a folder of your medical information, to be familiar with the contents of such letters, find out the meaning of medical terms used and take the folder with you when you go to an appointment.

If you have difficulty obtaining copies of your letters, contact your local Patient Advice and Liaison Service (PALS) or your local Independent Complaints Advisory Service (ICAS).

You can find out who these people are in your area by contacting your local Healthpoint. These are located in many large libraries.

Explaining your symptoms, their effects, your fears and worries to someone else is difficult. Telling a doctor is daunting for most women, be they teenagers or older women. Endometriosis is a particularly embarrassing disease and the symptoms can appear so unrelated, that most of us fail to tell our doctor about them. If you find that you are tongue-tied when you enter your doctor's surgery, go well-prepared and take a partner, relative or friend who knows your problems and will help you to communicate clearly.

### **PREPARATION:**

Most women with endometriosis first consult their doctor about problems with their periods. Keep a record of your periods for up to three months – see our Period Plot Chart to help you. Day one of your cycle is the first day of your monthly bleed. This will enable your doctor or nurse to identify any patterns that are occurring.

### **RECORD THE FOLLOWING:**

#### **About your period:**

- Number of days that each period lasts.
- Is the blood loss light or heavy?
- How many days are between periods?
- What colour the blood loss is.
- Is the blood loss consistent?
- If you have any other bleeding at time of period, i.e. from bowel, bladder, ear, eye, mouth, etc.
- If you have a vaginal discharge at any time, tell your doctor when it occurs and what colour it is, i.e. pink, brown, creamy and if it has an odour.
- Tell your doctor how many tampons or pads you use for each period.

#### **About your pain:**

- When does the pain occur? e.g.:before/during/after/between periods, every period, during/after intercourse, using tampons, constant.
- When were periods first painful?
- Type of pain? e.g.:ache, burning, stabbing, nagging, shooting, pinching, throbbing, intense, dull, numb, sharp, etc.
- How severe is the pain? e.g.: 1 = mild, 2 = moderate, 3 = distressing, 4 = horrible, 5 = unbearable.
- Where is/was the pain? abdomen, back, leg/s, other, could use pain map/diagram.
- What helps/relieves the pain? e.g. resting, lying down, relaxation, medication.
- Have you had time off work/school?
- Has the pain affected family/social activities? What do you think is causing the pain? cysts, implants, adhesions, scar tissue, etc.

### **About your fertility:**

- If you have been trying to become pregnant, tell your doctor how long it has been.
- Tell your doctor if anyone else in your family has had problems with infertility.

### **Family History:**

- Tell your doctor if anyone in your family has been diagnosed with endometriosis.

**This sounds a very long list, however most women will have some of the problems, but not all of them; so you only need to give a summary that will be clear and simple for example:**

*“My period lasts five days with 23 days between them. The bleeding is heavy for two days, then lighter for three days. I use X number of pads / tampons. I get a brown discharge for two days after my period. I get pain before / during / after my period and my painkillers don't help. I had to spend two days in bed last time and lost time off work. Intercourse is painful and it is affecting my relationship with my husband/partner. My pain is low in my tummy and is hot and burning and lasts a few days. I also get some bleeding from my bowel. My cousin has been diagnosed with endometriosis, and she says my problem sounds very much like hers, and advised me to come and see you for some help as I feel very tired and run down.”*

Some patients find it useful to take a chart to show a record of their symptoms and when they occur. This can be useful as a memory prompt. It's important that the doctor knows about all of your symptoms, including some that may seem very intimate. Such as making love is painful. It is also important to repeat your symptoms whenever you see a different doctor. Don't assume that the doctor has read all of your notes. Patients who are well prepared for an appointment/consultation are more likely to be taken seriously. Women with endometriosis, many of whom struggled a long time to get diagnosed, will tell others that the time spent documenting their symptoms on paper is time well invested.

Most doctors will be pleased to have such clear information and will discuss the information you have given. It may be that at this stage you will be offered the first line treatments for painful periods such as the contraceptive pill and / or anti-inflammatory tablets.

Whether you accept this, will depend on how severe your problems are. It is always acceptable for you to request a referral to a Gynaecologist for a definite diagnosis. Endometriosis can only be diagnosed by an operation called a laparoscopy. A leaflet describing this operation is available from Endometriosis SHE Trust (UK); please see our Leaflets Order Form. Meantime, it could be helpful to try pain control offered by your doctor whilst waiting for your gynae appointment.

If you have had previous treatment/s for endometriosis, the same advice would apply, but you need to add to your information any details regarding a worsening of the period problems (bleeding, pain, fertility, loss of work or education time, effect on relationships, etc).

### **AFTER DIAGNOSIS:**

Once your diagnosis has been made, the treatments that you are offered will should be explained. If you do not understand anything that has been offered to you, do ask for a clearer explanation of the surgery performed, side effects of treatments and the hopeful outcome of what is on offer, (see leaflet on medical treatments). It can often be advisable to ask for time to consider what has been offered, so that you are sure about the situation as it will affect you. Find out if there is a local support group and talk to other patients. If there isn't a group in your area, consider starting one – ask the Endometriosis SHE Trust (UK) for the leaflet “Starting a local independent support group”.

If you should get any side effects from your treatment, do seek advice, this can be from your Consultant, your GP or you can make good use of your Practice Nurse. Information is also available from us.

Endometriosis SHE Trust (UK) is able to discuss problems with you and so enable you to make informed choices regarding your treatment.

There is a Specialists Advisory Panel (SAP) who can answer your questions in writing. This is a very popular service, exclusive for members of Endometriosis SHE Trust (UK), please allow a few weeks for a reply.

### **THE ENIGMA OF ENDOMETRIOSIS:**

Remember to be fair to your doctor; endometriosis is not a disease that is fully understood. To-date there is no known cure for endometriosis; it is only possible to keep the problem under control. Every woman will respond differently to surgery and drug treatments, so it will not follow that the outcome for you will be the same as that for another female with endometriosis.

Treatment options will depend on your age and your wish to preserve your fertility as well as your personal preferences and the treatments currently used by your doctor. Always try to discuss things fully with your doctor, and also remember that no doctor can know everything about you or the disease.

### **PROBLEMS WITH YOUR GP:**

If you should have problems relating to your GP and feel that you need to change your doctor, it can be helpful to ask locally if anyone knows of a GP with an interest in endometriosis. You will need to go to your chosen GP practice and request to be registered. Most likely you will be asked to attend for a general medical check, and the Practice Nurse will take a basic medical history. If you are accepted as a patient, your new GP will request that your notes be sent to him/her. This is done via the local Family Health Services and can take a few weeks to complete, so be patient. You do not need to go back to your old GP to explain your reasons for moving.

### **CLARIFICATION OF LEGISLATION GIVING ACCESS TO HEALTH RECORDS:**

On 1 November 1991, the ACCESS TO HEALTH RECORDS ACT 1990 came into force.

The Act applies only to hand-written records, as access to computer records is already available. IT DOES NOT APPLY TO RECORDS WRITTEN PRIOR TO 1 NOVEMBER 1991 – unless they are required to clarify or interpret later records.